



University of
Salford
MANCHESTER

“Pacing does help you get your life back” : the acceptability of a newly developed activity pacing framework for chronic pain/fatigue

Antcliff, D, Keenan, A-M, Keeley, P, Woby, SR and McGowan, L

<http://dx.doi.org/10.1002/msc.1557>

Title	“Pacing does help you get your life back” : the acceptability of a newly developed activity pacing framework for chronic pain/fatigue
Authors	Antcliff, D, Keenan, A-M, Keeley, P, Woby, SR and McGowan, L
Type	Article
URL	This version is available at: http://usir.salford.ac.uk/id/eprint/60190/
Published Date	2021

USIR is a digital collection of the research output of the University of Salford. Where copyright permits, full text material held in the repository is made freely available online and can be read, downloaded and copied for non-commercial private study or research purposes. Please check the manuscript for any further copyright restrictions.

For more information, including our policy and submission procedure, please contact the Repository Team at: usir@salford.ac.uk.

RESEARCH ARTICLE

“Pacing does help you get your life back”: The acceptability of a newly developed activity pacing framework for chronic pain/fatigue

Deborah Antcliff^{1,2}  | Anne-Maree Keenan^{2,3} | Philip Keeley⁴ | Steve Woby^{5,6,7} | Linda McGowan²

¹Physiotherapy Department, Bury Care Organisation, Northern Care Alliance NHS Group, Bury, England, UK

²School of Healthcare, University of Leeds, Leeds, England, UK

³NIHR Leeds Biomedical Research Centre, Leeds, England, UK

⁴School of Nursing and Midwifery, Keele University, Keele, England, UK

⁵Research and Innovation Department, Northern Care Alliance NHS Group, Salford, England, UK

⁶School of Health and Society, University of Salford, Salford, England, UK

⁷Faculty of Science and Engineering, Manchester Metropolitan University, Manchester, England, UK

Correspondence

Deborah Antcliff, Physiotherapy Department, Bury Care Organisation, Northern Care Alliance NHS Group, Rochdale Old Road, Bury BL9 7TD, England, UK.
Email: D.Antcliff@leeds.ac.uk

Funding information

Health Education England/National Institute for Health Research (HEE/NIHR), Grant/Award Number: ICA-CL-2015-01-019

Abstract

Objectives: We have developed and feasibility tested an activity pacing framework for clinicians to standardise their recommendations of activity pacing to patients with chronic pain/fatigue. This study aimed to explore the acceptability and fidelity to this framework in preparation for a future trial of activity pacing.

Design: Acceptability and fidelity were explored using semi-structured interviews. Data were analysed using framework analysis.

Participants: Patients who attended a rehabilitation programme for chronic pain/fatigue underpinned by the framework, and clinicians (physiotherapists and psychological wellbeing practitioners) who led the programmes.

Results: Seventeen interviews were conducted, involving 12 patients with chronic pain/fatigue and five clinicians. The framework analysis revealed four deductive themes: (1) Acceptability of the activity pacing framework, (2) Acceptability of the feasibility study methods, (3) Processes of change and (4) Barriers and facilitators to activity pacing; and one inductive theme: (5) Perspectives of patients and clinicians.

Conclusions: The activity pacing framework appeared acceptable to patients and clinicians, and adherence to the framework was demonstrated. Processes of behaviour change included patients' regulation of activities through activity pacing. Barriers to pacing included work/social commitments and facilitators included identifying the benefits of pacing on symptoms. Different perspectives emerged between clinicians and patients regarding interpretations of symptom-contingent and quota-contingent strategies. The framework recognises fluctuations in symptoms of chronic pain/fatigue and encourages a quota-contingent approach with flexibility. Future work will develop a patient friendly guide ahead of a clinical trial to explore the effects of pacing.

KEYWORDS

acceptability, activity pacing, chronic fatigue, chronic pain, semi-structured interviews

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. Musculoskeletal Care published by John Wiley & Sons Ltd.

1 | INTRODUCTION

The management of complex conditions of chronic pain/fatigue includes varying and individualised strategies to facilitate behaviour changes and improve physical and psychological wellbeing (Bourke et al., 2014; British Pain Society, 2013; Pearson et al., 2020). Activity pacing is one such strategy that is commonly advised to increase individuals' participation in meaningful activities while managing symptoms (Abonie et al., 2020; Antcliff et al., 2019b; Nielson et al., 2013). Activity pacing involves modifying behaviours such as overactivity-underactivity (boom-bust) cycling, avoidance and excessive persistence. Such behaviours may be adopted in an attempt to prevent symptoms, as a reaction to symptoms or to distract from symptoms (Birkholtz et al., 2004). Behaviours that are driven by symptom severity (symptom-contingency) may leave individuals feeling out of control. Although activity pacing aims to regulate activities, the approach to activity pacing varies across clinicians, researchers and patients. As such, there is confusion regarding how pacing is instructed in a manner that optimises this self-care strategy (Andrews & Deen, 2016; Nielson et al., 2013).

We have developed an activity pacing framework using multi-staged mixed methodology, in accordance with the Medical Research Council (MRC) guidelines for developing complex interventions (Craig et al., 2008). With an inclusive approach to widen its relevance and usability, the pacing framework was developed for complex conditions with predominant symptoms of chronic pain and fatigue. Such conditions commonly present with overlapping symptoms, including anxiety, depression and reduced function, may co-exist and even predict the likelihood of further somatic comorbidities (Aggarwal et al., 2006; Bourke et al., 2014; McBeth et al., 2015; Warren et al., 2013). Based on the findings from a national online survey across healthcare professionals (Antcliff et al., 2019b) and a nominal group technique (consensus meeting between patients and clinicians) (Antcliff et al., 2019a), the framework comprises of two booklets: 'Theory and Overview', and 'Appendices and Teaching Guide'. The framework contains a conceptual model and definition of pacing, the aims and components of pacing, and incorporates activity diaries and goal setting to practise pacing. The model of pacing is underpinned by a quota-contingent operant approach (setting meaningful and realistic goals), with components of flexibility, choice and control. The framework moves away from principles of symptom-contingency due to the known multifactorial processes that can impact on individuals' experience of symptoms of chronic pain/fatigue, not just pathophysiological processes (Moseley, 2003; Nijs et al., 2012; Raja et al., 2020). The framework was developed to be relevant to people with a range of abilities, and apply to a variety of activities including work, housework, exercise, relaxation, socialising and hobbies.

The feasibility of using the activity pacing framework in a rehabilitation programme for chronic pain/fatigue, and the suitability of the questionnaires to measure activity pacing and symptoms were assessed in a repeated measures study (manuscript under review). Exploring acceptability is a key component of feasibility testing, and

greater acceptability is considered to improve adherence to complex interventions by clinicians and patients (Sekhon et al., 2017). Acceptability interviews are a useful method of process evaluation of fidelity and contextual factors that may influence the development and testing of a complex intervention (Craig et al., 2008; Moore et al., 2015; Sekhon et al., 2017). Therefore, the next stage in the development of the activity pacing framework involved interviewing patients and clinicians who were involved in the feasibility study.

1.1 | Aim

The aim of this study was to explore the acceptability of using the newly developed activity pacing framework in a rehabilitation programme for chronic pain/fatigue. Our specific objectives were to explore:

1. Patients' and clinicians' opinions on the acceptability of the activity pacing framework
2. Practical issues regarding the feasibility study methods to prepare for a future pacing trial
3. Processes of behaviour change (patients and clinicians)
4. Barriers and facilitators to activity pacing.

2 | METHODS

2.1 | Study design

Acceptability of the activity pacing framework was explored via semi-structured interviews with patients and clinicians. The theoretical qualitative methodology that underpinned this study was framework analysis since this was a pragmatic study to explore participants' opinions on the acceptability of the activity pacing framework. Framework analysis is widely used in policy and healthcare research, and holds advantages of deductive and inductive approaches (Gale et al., 2013; Ritchie et al., 2003). This study is reported in accordance with the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

2.2 | Participants

Participants included patients who consented to the feasibility study, completed the pre-treatment questionnaire booklet and attended both sessions on activity pacing (weeks 2 and 3) during the six-week rehabilitation programme. Eligible patients included those with an initial GP/hospital consultant referral with diagnoses of chronic low back pain, chronic widespread pain, fibromyalgia or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), with symptoms ≥ 3 months. Patients were required to read and write in English. Ineligible patients were those with evidence of a serious underlying pathology (e.g., current cancer diagnosis), or patients with severe

mental health or cognitive functioning issues. Patients were recruited via purposeful sampling to include those with varying conditions of chronic pain/fatigue, and patients who completed/did not complete the rehabilitation programme.

Purposeful sampling recruited clinicians who were qualified physiotherapists (Physio) and psychological wellbeing practitioners (PWP), who had attended a half-day training on using the activity pacing framework and implemented it in the rehabilitation programmes. Clinicians were observed delivering the pacing content of the rehabilitation programme for fidelity (by DA) and completed a fidelity checklist each programme to ensure their inclusion of key components of the framework.

2.3 | Recruitment

Patients were contacted via the telephone to invite them to take part in one acceptability interview after they attended the programme. Clinicians were invited to participate in person or via email/telephone. Patients/clinicians were sent written information regarding the study and provided written consent in advance of the interview and verbal consent at the start of the interview.

2.4 | Data collection

Participants were interviewed via the telephone or face-to-face in a healthcare setting, according to their preferences. Interview questions were developed by the research team that were informed by current literature on pacing and the findings from the previous stages of development of the activity pacing framework; and the questions were developed to facilitate an exploration of the acceptability of using the activity pacing framework in the clinical setting. Specifically, patients' interviews included discussions on how activity pacing was instructed, their opinions/challenges of pacing, using activity diaries/goal setting, and the ease of completing the questionnaire booklets. No further guides or prompts were administered to patients since the purpose of the interviews was to discuss their experiences. Clinicians' interviews discussed the content and clarity of the framework and its usability in the clinical setting; their opinions/experiences of activity pacing and any challenges of the feasibility study (see Figure 1). All interviews were digitally recorded and transcribed verbatim. Interview data were anonymised using unique study codes. Patients and clinicians were sent their interview transcription to check for accuracy. Field-notes were made during the interviews regarding any contextual factors and as prompts for data analysis (Morse & Field, 1996).

2.5 | Data analysis

The qualitative data from the transcriptions were analysed using framework analysis. Framework analysis is suitable for analysing

semi-structured interviews due enabling deductive processes to answer specific questions, while allowing for inductive processes to develop new ideas. The framework stages include: familiarisation with the data, identifying a thematic framework, indexing, charting and interpretation (Ritchie et al., 2003). The NVivo program (Version 12) was used to manage the qualitative data.

Data analysis was undertaken by the Chief Investigator (DA) working alongside a researcher (LMc) with an expertise in qualitative research methods. A patient representative independently indexed three interviews which were compared and discussed to reach an agreement and develop the indexing codes.

2.6 | Ethical approval

Ethical approval was granted by the London-Surrey Research Ethics Committee (18/LO/0655).

3 | RESULTS

Interviews occurred throughout the feasibility study (September 2018–November 2019) and patients were interviewed within approximately three months of starting the programme. The duration of interviews was 18–41 (mean = 32) minutes for patients and 20–39 (mean = 28) minutes for clinicians.

3.1 | Participant demographics

Of the 16 patients invited to participate, 12 consented and were interviewed (recruitment rate = 75.0%). Nine patients completed the programme and three did not. Reasons for non-completion included: unavailability, a family bereavement, and feeling younger and therefore disconnected from the group. All five clinicians (three physiotherapists and two PWPs) who were invited to participate, consented and were interviewed (see Table 1).

3.2 | Framework matrix

The Framework matrix contained five main themes. Four deductive themes addressed the objectives of the study: (1) Acceptability of the activity pacing framework, (2) Acceptability of the feasibility study methods, (3) Processes of change and (4) Barriers and facilitators to activity pacing. A fifth theme emerged inductively: (5) Perspectives of patients and clinicians. Initially, 48 codes were indexed. Following the cross-check with the patient advisor, four further codes were added ('other coping strategies', 'effects of pacing on others', 'understanding of condition' and 'mind-set'). When charting the data, codes were grouped together and summarised (see Table 2).

Examples of interview questions for patients*Understanding of activity pacing*

- How was the idea of activity pacing introduced to you?
- What is your understanding of activity pacing?
- Has your understanding of activity pacing changed since attending the programme?
- In your opinion, what does activity pacing involve?
- Is there anything else that you need to know about activity pacing, or anything that you do not understand about activity pacing?

Patients' opinions/experiences of activity pacing

- What are your opinions on activity pacing?
- Do you think that activity pacing is useful for you? (If so, please explain)
- Do you still try to pace your activities now that you no longer attending the programme?

Barriers to activity pacing

- Are there any barriers that prevent you from using activity pacing?
- Do you have any habits that you are findings difficult to change? (If so, please explain)
- Do you always pace your activities, or are there times that you do not pace? Is this a choice decision?

Activity pacing tools and study practicalities

- Did you complete an activity diary? If so, was this helpful?
- What are your opinions on the questionnaire booklets that you completed in the rehabilitation programme?

Examples of interview questions for clinicians*Opinions on pacing*

- What are your opinions of pacing? Do you think it is helpful for patients? Can you identify any reasons why some patients may benefit from pacing more than others?

Content and clarity of the activity pacing framework

- In your opinion, did the activity pacing framework explain the different components of pacing?
- Is there anything missing from the pacing framework? If so, what?
- In what ways was the framework similar to how you usually instruct pacing?
- In what ways was the framework different from how you usually instruct pacing?
- What improvements would you make to the pacing framework?

Barriers to adherence with the pacing framework

- Were there barriers to whether patients implemented pacing or not? If so, what do you think the main barriers were?
- Did you discuss the barriers to pacing with patients?

The training process and study practicalities

- How did you find the training session on teaching you how to use the pacing framework? For example, was it too long/short?
- How did you find the checklist of adherence to complete?
- How easy did you find the pacing framework to use in the clinical setting?

FIGURE 1 Examples of interview questions**(1) Acceptability of the activity pacing framework**

Patients found the instructions on pacing to be clear and thorough. Patients benefitted from pacing being introduced in the context of unhelpful behaviours, including illustrations of boom-bust, excessive persistence and avoidance behaviours:

"It was talked about and explained on a white board... showing a chart of the boom-bust cycles, and how to recognise when you're doing that and how to try and avoid it" (Patient3)

All clinicians reported the framework provided a comprehensive guide from which they could instruct patients, and there was nothing

either missing or redundant. They felt able to deliver the framework in their own style and in a meaningful way to patients, while maintaining fidelity to the framework. The conceptual model of the framework supported a rehabilitative approach which encouraged progression, together with aligning with other psychological approaches:

"It's progression too, so once you've established good pacing strategies, the idea is you want to progress in the future, which I think is always good at keeping people motivated to keep up with it." (Physio1)

"I think it's [pacing] also a good 'in-road' from the psychological type of things to just maybe challenging behaviours." (PWP2)

TABLE 1 Participant demographics

	Subgroup total
Patients' demographics	(n = 12)
Gender (male:female)	5:7
Age in years: range (mean)	30–75 (54)
Conditions (<i>patients could report more than one</i>):	
Chronic low back pain	10
Chronic widespread pain	4
Fibromyalgia	5
CFS/ME	2
Other (e.g., neck pain, shoulder pain)	2
Duration of condition in years: range (mean)	0.3–30.0 (13.0)
Employment status:	
Full-time	3
Part-time	2
Retired	4
Not working due to condition	1
Other	2
Clinicians' demographics	(n = 5)
Gender (male:female)	4:1
Age in years: range (mean)	29–53 (40)
Profession:	
Physiotherapist (Physio)	3
Psychological wellbeing practitioner (PWP)	2
Duration of specialism in chronic pain/fatigue (in years): range (mean)	2.0–14.0 (6)

Clinicians and some patients found the activity diaries a useful tool to recognise behaviours. Three patients did not find activity diaries helpful due to completing other paperwork, or self-reported low motivation or depression. Clinicians thought goal setting was helpful for patients to practise pacing, to individually tailor pacing and to facilitate patients to monitor their own progress:

“Because of the way we do the goal setting, we do take time...pacing isn't just an abstract concept in session, it's about how are you going to go away and apply it.” (PWP2)

Patients set goals to socialise with friends, try varying exercises, protect time for hobbies and relaxation, and gradually try activities they had been avoiding due to symptoms. Seven patients reported benefits of goals to embed the pacing theory into practice:

“I think they explained it [pacing] really well on the course...and like every week you had a refresher and you went over whether you'd done your goals and if not, you could set realistic ones.” (Patient1)

Clinicians considered the framework components of activity pacing to be acceptable, including: recognising current behaviours, finding baselines, self-compassion, being flexible and gradually progressing activities. Patients reported key components of pacing including: breaking down tasks, saying ‘no’, being kind to themselves, using rest breaks, doing something each day, developing a structure and gradually building up activities. Patients thought that pacing would look different for everyone:

To me it means like, you have got an activity or job you are doing, you just do it in a certain amount of time if you can, if not, just leave it and go to something else that wants doing. I think it's up to each individual the pacing, what time limit they want to set on things and, if you have not got a time limit, it's fine. (Patient2)

“I hadn't heard about it [pacing] until I started on the course, but it's also made me learn to say no to people as well...But people can't see that you're in pain, 'cause it's not visible.” (Patient1)

TABLE 2 Overview of themes and subthemes from the framework analysis

Themes	Subthemes	Additional codes	Examples
(1) Acceptability of the activity pacing framework	Activity pacing framework; definition and model	Clinical use; suggestions for improvement	"You can come up with your own interpretations....and read a bit of an article here or something there, but this was a very clear formula and guidance." (Physio2)
	Activity pacing tools: activity diary and goal setting		"Not everyone completed it [activity diary] but the ones that did...it helped them sometimes identify if they had a boom-bust or an over-activity type of behaviour...it allowed us to then look at goal setting from their point of view" (Physio1)
	Components of activity pacing; other coping strategies		"If I plan ahead and put things in diaries, and if I know I've got a busy week, you know... think ahead of building in a break for myself somewhere." (Patient12)
	Instructing patients on pacing; types of activities that are paced	Opportunities to practise pacing	"I did like the way they explained it as well with the diagrams and in terms of the graphs they were showing me...the different variations and what people think they should do, compared to what pacing actually really is." (Patient10)
(2) Acceptability of the feasibility study methods	Clinician training; checklist and observation		"The teaching was really clear and we had the clear resources and that's one of the benefits of a framework, you know. We are taught within a framework." (PWP2)
	Questionnaire booklets; study challenges/successes		"They [questionnaires] weren't difficult. I think sometimes they would tell you, depending on either the day I was having or what had happened the night before, your mood and things." (Patient7)
(3) Processes of change	Change in clinicians' understanding/teaching of activity pacing	A priori knowledge/previous instruction of pacing;	"In the past, it [pacing] would just been seen as a talk you did on week two of programme, as opposed to now, which is something that's fully engrained, not only in the pain management programme... throughout the six weeks, but also within my day-to-day work." (Physio1)
	Change in patients' understanding of activity pacing; changes in patients' behaviours	A priori knowledge of pacing; new understanding of pacing	"I struggled with the previous one [pacing for ME/CFS]...it was very gentle and I was capable of doing more, so I felt like sometimes it didn't really apply to me...So I definitely think it was more realistic: the pain management one...It was more like doing what you can, basically, pushing yourself when you know you can be pushed but also toning things down if you can't." (Patient6)
	Effects of changing behaviours on activity levels	Doing more through pacing; doing less; being consistent	"Pacing will help you not stress out and feel bad...you'll be more level, rather than have the highs and the lows with your pain. And then to work out a way to achieve more...something that you like." (Patient4)
	Continuation of pacing after the programme. Short-term vs. long-term		"It was certainly well put together and it was well thought out and it was well presented...And I think it was very

TABLE 2 (Continued)

Themes	Subthemes	Additional codes	Examples
	Mind-set and attitude	Understanding of condition	<p><i>beneficial. The problem with all these things is actually putting it into effect after you've left." (Patient5)</i></p> <p><i>"To give people a sense of, this is not something that you can wait for somebody else to come along and sort out for you. That there are things that you can sort out yourself, that might not cure you, but they certainly make your condition a lot easier to live with." (Patient9)</i></p>
(4) Barriers and facilitators to activity pacing	Challenges of/barriers to pacing; individual differences	Patients' and clinicians' perspectives	<i>"Before I would have been very like, a little bit of a control freak...if there's certain things that I'm used to doing and I do it a certain way, like I don't really want to delegate. So that would probably stop me [pacing] sometimes or just, feeling like I have to do things." (Patient6)</i>
	Effects of pacing	Patients' and clinicians' perspectives on the effects on the individual and others	<i>"But pacing for me was a bit of a wake-up call, if I'm honest with you. Yes, you've got your pain, but this will help. Doing nothing and having medication, yeah, if you can manage, but it's not really a life. Pacing does help you get your life back." (Patient10)</i>
(5) Perspectives of patients and clinicians	Symptom- vs. quota-contingency		<i>"The concept of energy consumption, no, don't do it to conserve energy. People often are worried about using their energy levels. So we try to go for pleasure and for satisfaction, quality of life and looking to progress that gently over time." (Physio2)</i>
	Flexibility vs. rigidity		<i>"Then life just throws a curve ball at you and it can be difficult to continue to pace... that's where the flexibility comes in...it ties in with...self-compassion that we work on from a psychology point of view... Rather than being really rigid." (Physio3)</i>
	Choice and control		<i>"People make their own decisions, don't they? So they're going to make their choices about how they go about things so we're hopefully partnering them in that." (Physio2)</i>
	Acceptance		<i>"I don't want to surrender to having a life of just lying in bed. And I know the pain is not going to kill me. It's not very pleasant and it hurts. But then...I need to do stuff, I need to have what life I can have, the best I can." (Patient8)</i>

(2) Acceptability of the feasibility study methods

Clinicians reported that the pacing framework training session, the Theory and Teaching Guide booklets, and fidelity observation feedback were sufficient. They commented that although the fidelity

checklist was a useful reminder at first, it became redundant as their experience increased.

Clinicians reported challenges for some patients to complete the questionnaire booklets in a timely manner due to the number of questions. All patients reported the questionnaires were self-

explanatory and for some, they helped their self-reflection. However, others commented on repetition among the questionnaires, or had difficulties rating symptoms that can vary.

Challenges to rolling out the research more widely were suggested to include potential resistance among clinicians to change practices:

"It's [pacing's] an integral part of a pain management programme and I think everything needs looking at over time...There'll always be resistance to things and change...but, actually, it's for the benefit of patients." (Physio2)

A success of the study was the perception that this research would help to develop treatments:

"It is good because I think people with underlying conditions, you are stuck in a loop where medication from a doctor's perspective is one of the only ways to control it. In many years to come, you never know, it may change. And if people like yourself weren't looking into certain ways to manage it, I think we'd all end up a lot worse off." (Patient10)

(3) Processes of change

Eight patients had no a priori knowledge of pacing. Of the four patients who had previously heard of pacing, they perceived it would be something they did naturally. However, some misunderstandings of pacing were modified after attending the programme:

"...Before going to the programme I was just stuck in a situation where I'd do what work I could when I could... and then suffered for it; and I didn't really think about it the same way as when it's explained to you...So, whereas I thought I was pacing myself naturally, in a sense I wasn't." (Patient3)

Two patients described avoidance behaviours prior to treatment, driven by their symptoms, co-morbidities and previous misinterpretation about harmful/safe activities. Five patients described behaviours that aligned most closely with overactivity-underactivity cycling prior to the programme. Contributing to these behaviours were personality traits such as being stubborn, self-driven rules, aiming to please others or occupation. Three patients described behaviours most befitting of excessive persistence, driven by work obligations, perfectionism, low self-esteem, old habits and perceived opinions of others:

"I could immediately recognise the fact that I was, to a greater extent, an over-doer, rather than a boom and buster. Because, I wouldn't allow myself to bust. I'd just keep booming, and that can be just as, sort of, disabling in terms of the health outcomes." (Patient9)

This patient explains his excessive behaviours:

"In a way there's a, sort of, psychosocial aspect to it... from my family background we were always, to some extent, inculcated into the idea of it's important what other people think of you....And, now I've started to come to the conclusion that, yeah, that is still important, but it's not the be-all and end-all" (Patient9)

Patients reported changing their behaviours after being instructed on pacing. Those with previous avoidance and boom-bust behaviours undertook a more consistent approach to activities:

Before that course I actually went on, I would have been just quite happy to sit and do nothing. But I am aware about the fact that I do need to actually...no matter how little it is, it needs to be doing something. (Patient7)

"Well, it's just that I pace them out more, I just take my time. I just don't rush in like, you know, a bull in a China shop. I just go and do them, and then...I have a rest after doing so much. And I might even leave it 'til the following day before I finish." (Patient11)

Patients with excessive persistence behaviours modified their behaviours by purposefully stopping activities before overdoing things and shifting away from perfectionism. Patients reported a new understanding of pacing to include being kinder to themselves and creating routines. They identified that implementing greater consistency in their activities had impacted positively on their symptom management. After initiating changes to their behaviours, patients recognised the importance of their long-term continuation:

"Pacing for me is the commitment to yourself. And not just yourself can feel the benefits but everyone else around you will. I think for me, pacing is something that you control, it doesn't have to be set exercise, set time limits....Ultimately, if you're doing nothing now, creating pacing and pushing yourself and giving yourself targets, that sense of achievement when you meet your goals, you'll continue it and you'll feel a lot better." (Patient10)

Through adhering to a pacing framework, clinicians' practice changed to undertake more in-depth discussions with patients regarding the different behaviours as a context to pacing:

"It's [pacing framework] a lot more detail to it and it's a lot more applied as well. So, you're not just looking at the boom and bust cycle, you are looking at...how things might plateau or persistently overdoing things like that. So, it's certainly a lot of more applicable

people...not everyone is a one size fits all thing. And you don't want to feel excluded from pacing because they don't fit the stereotypical boom and bust." (PWP2)

(4) Barriers and facilitators to activity pacing

Patients' perspectives of barriers to implementing pacing included challenges of pacing during social activities; work/family commitments; and other people being over-solicitous or less understanding. Other barriers included personality traits and habits, for example, wanting to complete tasks, or not wanting to delegate or be perceived as lazy. Two patients considered that other illnesses, severe pain, or set-backs may form barriers to pacing. Emotional state may also influence patients' implementation of pacing:

"But I do still have a problem...with the mental state, and I can go off the rails and have a lack of enthusiasm. ...have a few days where things stop totally; and if they slip back, well then I'll just have to pick up and start again...But it is something that is conscious on my mind...to try and get a routine and more pacing in my life." (Patient3)

Similarly, clinicians' perspectives of challenges to pacing included patients' mental/psychological health, co-morbidities and changing ingrained behaviours. Clinicians' perspectives on facilitators to pacing included encouraging flexibility in pacing and using pacing to assist gradual increases in activity, rather than it being punitive, limiting or boring:

"I remember I did a CBT [cognitive behavioural therapy] for physios' course and she described pacing as almost being quite boring: 'You're just going to do the same kind of thing every day'. I was like, oh that's a far more difficult sell to patients. I think a lot of it is about getting buy in. So, if you're giving them that opportunity to be a little bit more flexible, you're giving them a little bit more ownership of it. I think that's more positive." (Physio3)

Patients' perceived facilitators to pacing included their own determination. Many felt encouraged to continue to pace when they noticed how pacing improved their symptom management, reduced set-backs, structured their daily routines and enabled their participation in a variety of activities, together with when their family noticed their improvements:

"Now I feel fitter, I'm exercising a lot, sleep a bit better actually. Don't feel like you're as much of a burden, because you can do what you want to do through pacing." (Patient4)

All patients believed that pacing was relevant to them, including patients across a range of ages and working statuses. Patients believed that pacing could be relevant to various medical conditions and also for those without a medical condition.

(5) Perspectives of patients and clinicians

Some differing opinions emerged inductively between clinicians and patients, for example, regarding interpretations of quota-contingent or symptom-contingent pacing. Clinicians recommended quota-contingency as an appropriate approach to activity pacing for chronic pain/fatigue:

I think quotas is a very good way to do it. It allows people to quantify and move away from symptoms so to time, to frequency, to level. Whatever it is, to actually name something different to symptoms and focus on something bigger and wider than just the pain experience; life (Physio2)

Following receiving the clinicians' instructions on pacing, most patients shifted towards quota-contingency with an awareness of symptoms:

There was the 12 exercises, and they [clinicians] said to sort of do it for a minute, rest for a minute. But they said if you feel like you can do more, do more, but then if that's too much, then lower it. So it was kind of like teaching you to just see how you feel...So if something's too much then take it down a notch, if it's not enough then take it up a notch. So that was quite good, and also the mental side of it. (Patient6)

Patients understood the need to find their own baselines, undertake achievable amounts and to accept that things may not get completed that day. However, for some, such quota-contingent concepts required listening to symptoms:

"[Pacing is] being kind to yourself I'd say, listen to your body more and don't beat yourself up if you actually can't do something, but try to do something each day. Not just a chore, but maybe is a pleasure, you know, that you enjoy. If it's only going to the garden centre with somebody. So, try and pace it, where you've got to...be more in control and not just, sort of go for it." (Patient8)

Furthermore, a more symptom-contingent approach may be necessary for some acute conditions:

"When you're in a setting where you are encountering more acute pain...you do tend to be a little bit more symptom aware, or symptom driven. Whereas with this [framework], actually, the pain's there, you're going to do what you're going to do with the pain." (Physio3)

Clinicians and patients had convergent opinions towards implementing activity pacing with a sense of flexibility and decision-making regarding when to pace, in keeping with the framework. Patients commented that while recognising the benefits of pacing, they might still choose to continue an activity for longer periods through enjoyment, pride, or a sense of living their life:

"For me personally...it's doing what you can and continuing it to a level that works for you because ultimately life changes doesn't it, the days change" (Patient10)

I think there are definitely times when not pacing is worth it, especially from the psychological point of view. (PWP1)

As per the framework, clinicians tried to teach patients that pacing involved a greater sense of choice and control, and in part, due to moving away from symptom-contingency:

"I always try and aim, when patients come in and they present that the pain is in control of them, I try and give them the impression that they're going to be in control of the pain. I think this [pacing] strategy put that's into place." (Physio1)

Both clinicians and patients recognised the need for acceptance of the condition and their abilities, and applying self-compassion in order to initiate activity pacing:

"I think pacing is part of accepting and managing the condition, and if you don't want to accept it, you're going to struggle to do the pacing side of it." (Physio3)

"I've got a back condition; you know there is not a magic bullet that's going to sort it out. And generally, understanding that. You know that the condition that you have is long-term and is more or less permanent, and just becoming reconciled to it without feeling that that is necessarily a totally debilitating condition." (Patient9)

4 | DISCUSSION

This study explored the acceptability of a new activity pacing framework, fidelity to the framework and contextual factors as a process evaluation of this complex intervention development. Acceptability relates to clinicians' and patients' perception of the appropriateness of an intervention based on their expectations or experiences (Sekhon et al., 2017). The framework appeared acceptable for clinicians in terms of its conceptual model, and it had clinical

utility due to the applied approach (e.g., goal-setting). The framework provided a structure and standardised guide for what is considered an ambiguous coping strategy (Gill & Brown, 2009; Nielson et al., 2013). Clinicians' feedback on the key themes of activity pacing added evidence of their fidelity to the framework. They commended the framework on including psychological approaches and experiential learning. Such components are crucial, since patients' symptoms encompass a personal experience, that is, underpinned by complex bio-psychosocial factors and a learned response to pain (Raja et al., 2020). Patients' feedback alluded to their adherence to the framework, confidence to implement pacing, autonomy to manage their health conditions and perceived benefits. Such findings link with the Theoretical Framework of Acceptability (TFA) constructs of: affective attitude, intervention coherence, perceived effectiveness and self-efficacy (Sekhon et al., 2017).

Clinicians' process of behaviour change through using the framework included leading thorough discussions with patients on avoidance and excessive persistence, not just boom-bust behaviour. This context to pacing facilitated the individualised tailoring of pacing. The benefits of tailored pacing may include lower fatigue and more consistency of activity levels (Murphy et al., 2010, 2012).

Patients' process of behaviour change was enhanced by discussing pacing over two sessions and practising pacing throughout the programme. Patients reported benefits of recognising their behaviours, considering what drove these behaviours and the long-term impact of reactive behaviours. This cognitive shift enabled behaviour changes through patients selecting their appropriate facets of pacing, for example, breaking down tasks for excessive persistence and attempting activities for avoidance behaviours. There was a sense of optimism about pacing; and patients' recognition of the positive outcomes of pacing and achievement of goals aligns with the quota-contingent operant approach to pacing (Nielson et al., 2013).

Participants' perceptions of barriers and facilitators to pacing relate to the TFA constructs of 'burden' and 'opportunity costs' (Sekhon et al., 2017). These comprised of environmental and social influences, together with psychological and emotional factors. Other barriers included changing habitual overactive/underactive behaviours or personality traits, similarly to other studies (Andrews et al., 2015; Cane et al., 2016). Facilitators to pacing included patients' and their families' recognition of improved emotional, cognitive and physical wellbeing.

Some differing opinions emerged between clinicians' and patients' perspectives of symptom- and quota-contingency. Quota-contingency supports the principles of pain education, including explanations that symptom severity may not always be explained by tissue damage (Raja et al., 2020); and endorses the aim of rehabilitation programmes to increase function rather than directly reduce symptoms (British Pain Society, 2013). Furthermore, a reduction in pain may not be a feasible expectation of pacing (Guy et al., 2019). However, the impact of symptoms cannot be ignored while pacing. To the contrary, symptom severity plays a role in pacing when patients identify baselines of manageable activities. Baselines are centred on individuals' tolerance levels and undertaking activities in a manner

that does not trigger a set-back (Nielson et al., 2013). Symptoms of chronic pain/fatigue can also fluctuate. Therefore, the framework encourages flexibility within a quota-contingent approach; to acknowledge symptoms while ensuring pacing remains relevant and achievable. However, confusion may arise between clinicians' instructions of quota-contingency with flexibility, and patients' interpretation as symptom-contingency.

Clinicians and patients had convergent opinions that flexibility was an important component of setting goals and when making considered decisions whether or not to pace. Similarly, principles of psychological flexibility include active decision-making to change or persist with an action with consideration of individuals' goals, emotions and situation (McCracken, 2013). Participants were aligned in understanding that pacing involved acceptance and self-compassion. Components of acceptance contained in the framework, such as enabling appropriate adaptations of activities and encouraging satisfaction with achievements are important components of pacing (Andrews et al., 2015; Cane et al., 2016), and rehabilitation programmes as a whole (Kallhed & Mårtensson, 2018). Furthermore, participants agreed that pacing facilitated a sense of choice and control, as recognised in other pacing literature (Birkholtz et al., 2004; Pearson et al., 2020).

Pacing may have been confused by the minority of patients as resting after over-activity, or considered to be a natural response. However, 'naturalistic pacing' may be underpinned by symptom-contingent and reactive behaviours such as going slow and steady or taking breaks after activity rather than pre-planned pacing as a learned strategy (Murphy & Kratz, 2014). Naturalistic pacing has previously been associated with reduced function and increased symptoms (Andrews et al., 2012; Guy et al., 2019; Murphy & Kratz, 2014). Furthermore, we believe that pacing comprises of more than simply resting after activity, slowing down or taking breaks (Antcliff et al., 2018).

4.1 | Strengths and limitations

Whilst the sample size was relatively small, it was in keeping with qualitative approaches. Purposeful sampling enabled a variety of participants to be involved including clinicians of different professions and patients of varying ages, conditions and abilities, together with those who did/did not complete the programme. Through including diverse opinions, rich data were collected; and purposeful samples may reduce sampling bias (Ayres, 2007; Tong et al., 2007).

Bias may have arisen during the data collection and analysis since the lead author undertook all of the interviews and led the framework analysis. Participants were informed that the lead author is a physiotherapist and researcher in chronic pain/fatigue. The author did not routinely deliver the rehabilitation programmes, but may have had contact with some patients during their treatment. To reduce bias and increase the patient voice, a subset of interviews were coded independently by a patient advisor. Consequently, new codes/subthemes were added which may reflect the lived experience of implementing pacing.

5 | CONCLUSIONS

We have developed a comprehensive activity pacing framework to facilitate the modification of behaviours to support the management of chronic pain/fatigue. The framework appears clinically usable and the conceptual model appears acceptable. The framework encourages quota-contingent goal setting with flexibility, acceptance, choice and control to create meaning and relevance for patients. Future study will assess the effects of using the activity pacing framework in a clinical trial.

ACKNOWLEDGEMENTS

We would like to acknowledge all of the participants who took time to provide their valuable opinions. We would like to thank the patient representative for her opinions on the data analysis. This study is funded by Health Education England/National Institute for Health Research (HEE/NIHR) [Clinical Lectureship (ICA-CL-2015-01-019)]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

CONFLICT OF INTEREST

All authors declare no conflict of interest.

ETHICS STATEMENT

Ethical approval was granted by the London-Surrey Research Ethics Committee (18/LO/0655).

AUTHOR CONTRIBUTIONS

All authors contributed to the concept and design of the study, and the interpretation of the data. Dr Antcliff was responsible for the acquisition of data, and Dr Antcliff and Professor McGowan were involved in the data analysis. All authors were involved in drafting the manuscript and approved the revised manuscript ahead of publication. All authors agree to be accountable for all aspects of the work regarding accuracy and integrity.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Deborah Antcliff  <https://orcid.org/0000-0002-9771-8232>

REFERENCES

- Abonie, U. S., Edwards, A. M., & Hettinga, F. J. (2020). Optimising activity pacing to promote a physically active lifestyle in medical settings: A narrative review informed by clinical and sports pacing research. *Journal of Sports Sciences*, 38(5), 590–596. <https://doi.org/10.1080/02640414.2020.1721254>
- Aggarwal, V. R., McBeth, J., Zakrzewska, J. M., Lunt, M., & Macfarlane, G. J. (2006). The epidemiology of chronic syndromes that are frequently unexplained: Do they have common associated factors? *International Journal of Epidemiology*, 35, 468–476. <https://doi.org/10.1093/ije/dyi265>

- Andrews, N. E., & Deen, M. (2016). Defining activity pacing: Is it time to jump off the merry-go-round? *The Journal of Pain*, 17, 1359–1362. <https://doi.org/10.1016/j.jpain.2016.05.001>
- Andrews, N. E., Strong, J., & Meredith, P. J. (2012). Activity pacing, avoidance, endurance, and associations with patient functioning in chronic pain: A systematic review and meta-analysis. *Archives of Physical Medicine and Rehabilitation*, 93, 2109–2121, e2107. <https://doi.org/10.1016/j.apmr.2012.05.029>
- Andrews, N. E., Strong, J., Meredith, P. J., Gordon, K., & Bagraith, K. S. (2015). It's very hard to change yourself. *Pain*, 156, 1215–1231. <https://doi.org/10.1097/j.pain.0000000000000161>
- Antcliff, D., Keeley, P., Campbell, M., Woby, S., Keenan, A.-M., & McGowan, L. (2018). Activity pacing: Moving beyond taking breaks and slowing down. *Quality of Life Research*, 27, 1933. <https://doi.org/10.1007/s11136-018-1794-7>
- Antcliff, D., Keenan, A. M., Keeley, P., Woby, S., & McGowan, L. (2019a). Engaging stakeholders to refine an activity pacing framework for chronic pain/fatigue: A nominal group technique. *Musculoskeletal Care*, 17(4), 354–362. <https://doi.org/10.1002/msc.1430>
- Antcliff, D., Keenan, A. M., Keeley, P., Woby, S., & McGowan, L. (2019b). Survey of activity pacing across healthcare professionals informs a new activity pacing framework for chronic pain/fatigue. *Musculoskeletal Care*, 17, 335–345. <https://doi.org/10.1002/msc.1421>
- Ayres, L. (2007). Qualitative research proposals—Part III. *Journal of Wound, Ostomy and Continence Nursing*, 34(3), 242–244. <https://doi.org/10.1097/01.WON.0000270816.99318.3b>
- Birkholtz, M., Aylwin, L., & Harman, R. M. (2004). Activity pacing in chronic pain management: One aim, but which method? Part one: Introduction and literature review. *British Journal of Occupational Therapy*, 67, 447–452.
- Bourke, J. H., Johnson, A. L., Sharpe, M., Chalder, T., & White, P. D. (2014). Pain in chronic fatigue syndrome: Response to rehabilitative treatments in the PACE trial. *Psychological Medicine*, 44(7), 1545–1552. <https://doi.org/10.1017/S0033291713002201>
- British Pain Society. (2013). *Guidelines for pain management programmes for adults*. London: British Pain Society.
- Cane, D., McCarthy, M., & Mazmanian, D. (2016). Obstacles to activity pacing: Assessment, relationship to activity and functioning. *Pain*, 157, 1508–1514. <https://doi.org/10.1097/j.pain.0000000000000553>
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., & Medical Research Council, G. (2008). Developing and evaluating complex interventions: The new medical research Council guidance. *BMJ*, 337, a1655. <https://doi.org/10.1136/bmj.a1655>
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13, 117. <https://doi.org/10.1186/1471-2288-13-117>
- Gill, J. R., & Brown, C. A. (2009). A structured review of the evidence for pacing as a chronic pain intervention. *European Journal of Pain*, 13, 214–216. <https://doi.org/10.1016/j.ejpain.2008.03.011>
- Guy, L., McKinstry, C., & Bruce, C. (2019). Effectiveness of pacing as a learned strategy for people with chronic pain: A systematic review. *American Journal of Occupational Therapy*, 73(3). <https://doi.org/10.5014/ajot.2019.028555>
- Kallhed, C., & Mårtensson, L. (2018). Strategies to manage activities in everyday life after a pain rehabilitation program. *Scandinavian Journal of Occupational Therapy*, 25(2), 145–152. <https://doi.org/10.1080/11038128.2017.1283442>
- McBeth, J., Tomenson, B., Chew-Graham, C. A., Macfarlane, G. J., Jackson, J., Littlewood, A., & Creed, F. H. (2015). Common and unique associated factors for medically unexplained chronic widespread pain and chronic fatigue. *Journal of Psychosomatic Research*, 79(6), 484–491. <https://doi.org/10.1016/j.jpsychores.2015.10.004>
- McCracken, L. M. (2013). Committed action: An application of the psychological flexibility model to activity patterns in chronic pain. *The Journal of Pain*, 14(8), 828–835. <https://doi.org/10.1016/j.jpain.2013.02.009>
- Moore, G. F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati T., Wight D., & Baird J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *BMJ*, 350, h1258. <https://doi.org/10.1136/bmj.h1258>
- Morse, J. M., & Field, P. A. (1996). *Nursing research: The application of qualitative approaches* (2nd ed.). London: Chapman & Hall.
- Moseley, G. L. (2003). A pain neuromatrix approach to patients with chronic pain. *Manual Therapy*, 8(3), 130–140. [https://doi.org/10.1016/s1356-689x\(03\)00051-1](https://doi.org/10.1016/s1356-689x(03)00051-1)
- Murphy, S. L., & Kratz, A. L. (2014). Activity pacing in daily life: A within-day analysis. *Pain*, 155(12), 2630–2637. <https://doi.org/10.1016/j.pain.2014.09.028>
- Murphy, S. L., Lyden, A. K., Smith, D. M., Dong, Q., & Koliba, J. F. (2010). Effects of a tailored activity pacing intervention on pain and fatigue for adults with osteoarthritis. *American Journal of Occupational Therapy*, 64, 869–876.
- Murphy, S. L., Smith, D. M., & Lyden, A. K. (2012). Type of activity pacing instruction affects physical activity variability in adults with symptomatic knee or hip osteoarthritis. *Journal of Physical Activity and Health*, 9(3), 360–366. <https://doi.org/10.1123/jpah.9.3.360>
- Nielson, W. R., Jensen, M. P., Karsdorp, P. A., & Vlaeyen, J. W. S. (2013). Activity pacing in chronic pain. *The Clinical Journal of Pain*, 29, 461–468. <https://doi.org/10.1097/AJP.0b013e3182608561>
- Nijs, J., Meeus, M., Van Oosterwijck, J., Ickmans, K., Moorkens, G., Hans, G., & De Clerck, L. S. (2012). In the mind or in the brain? Scientific evidence for central sensitisation in chronic fatigue syndrome. *European Journal of Clinical Investigation*, 42(2), 203–212. <https://doi.org/10.1111/j.1365-2362.2011.02575.x>
- Pearson, J., Whale, K., Walsh, N. E., Derham, S., Russell, J., & Cramp, F. (2020). Fibromyalgia Self-Management: Mapping the behaviour change techniques used in a practice-based programme. *Musculoskeletal Care*, 18(3), 372–382. <https://doi.org/10.1002/msc.1470>
- Raja, S. N., Carr, D. B., Cohen, M., Finnerup, N. B., Flor, H., Gibson, S., Keefe, F. J., Mogil J. S., Ringkamp M., Sluka K. A., Song X.-J., Stevens B., Sullivan M. D., Tutelman P. R., Ushida T., & Vader K. (2020). The revised international association for the study of pain definition of pain: Concepts, challenges, and compromises. *Pain*, 161, 1976. <https://doi.org/10.1097/j.pain.0000000000001939>
- Ritchie, J., Spencer, L., & O'Connor, W. (2003). Carrying out qualitative analysis. In J. Ritchie, & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 219–262). London: Sage Publications Ltd.
- Sekhon, M., Cartwright, M., & Francis, J. J. (2017). Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. *BMC Health Services Research*, 17(1), 88. <https://doi.org/10.1186/s12913-017-2031-8>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Warren, J. W., Langenberg, P., & Clauw, D. J. (2013). The number of existing functional somatic syndromes (FSSs) is an important risk factor for new, different FSSs. *Journal of Psychosomatic Research*, 74(1), 12–17. <https://doi.org/10.1016/j.jpsychores.2012.09.002>

How to cite this article: Antcliff D, Keenan AM, Keeley P, Woby S, McGowan L. "Pacing does help you get your life back": The acceptability of a newly developed activity pacing framework for chronic pain/fatigue. *Musculoskeletal Care*. 2021;1–12. <https://doi.org/10.1002/msc.1557>